No. 06-637

# In The Supreme Court of the United States

BOARD OF EDUCATION OF THE CITY SCHOOL DISTRICT OF THE CITY OF NEW YORK,

*Petitioner,*

v.

TOM F. on behalf of GILBERT F., a minor child,

*Respondent.*

**On Writ Of Certiorari To The United States Court Of Appeals For The Second Circuit**

## *AMICUS CURIAE* BRIEF OF AUTISM SPEAKS IN SUPPORT OF RESPONDENT


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## INTEREST OF *AMICUS CURIAE*[1]

*Amicus curiae* Autism Speaks is a not-for-profit organization dedicated to increasing awareness of autism spectrum disorders; funding research into the causes, prevention, treatments and potential cures for autism; and advocating for the needs of affected families. Following mergers with other national autism organizations, Autism Speaks is now the largest not-for-profit organization in the world by resources dedicated to autism research, education and treatment and has chapters across the United States, Canada, and the United Kingdom. Autism Speaks works closely with federal, state and local governments, as well as the U.S. military, to meet the needs of the ever-growing population of children with autism and parents of children with autism for access to treatment and education.

Autism Speaks can offer valuable insights into the special educational challenges faced by children with autism and their families and the potential impact of the Court's decision on thousands of families across the nation. Early, intensive and effective special education services are critical to give a young child the chance to remediate and overcome the symptoms of autism and to grow into a productive, self-sufficient member of society. The result advocated by the Petitioner would jeopardize parents' ability to secure appropriate services for their child at precisely the point when an appropriate program

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[1] Pursuant to this Court's Rule 37.6 we note that no part of this brief was authored by counsel for any party, and no person or entity other than Autism Speaks, its members, or its counsel made a monetary contribution to the preparation or submission of the brief. This brief was filed with the written consent of all parties.

is most critical and, conversely, when the damage caused by an inappropriate placement is the gravest. The harm that an inappropriate program can cause to a child's development during this window of opportunity can never be fully corrected.

## PRELIMINARY STATEMENT

Parents of children with autism simply cannot allow their child to languish in an inappropriate setting when every passing moment means the loss of developmental opportunities that can never be regained. For these children and their parents, every moment counts. Early and intensive educational intervention is critically important to the future of a child with autism. Almost all children with autism will benefit from early and appropriate services, and a significant number will even be able to join regular education classrooms and grow into adults able to enjoy independent and productive lives. But the window of opportunity is widest when the child is young, and the damage to the child's development if this opportunity is not seized can never be undone. Mistakes at this critical juncture are costly and often irremediable – parents and educators simply cannot afford to learn geology the morning after the earthquake.[2]

For more than twenty years, the Individuals with Disabilities Education Act ("IDEA") and its predecessor

[2] "We learn geology the morning after the earthquake, on ghastly diagrams of cloven mountains, up-heaved plains, and the dry bed of the sea." Ralph Waldo Emerson, *Considerations by the Way*, in THE CONDUCT OF LIFE 1088 (1860).

statutes have allowed parents of children with disabilities to recover reasonable expenses they are forced to incur when they reject a school district's inappropriate placement and secure proper services at their own expense. This important remedy provides relief to parents who have made the courageous and risky decision to dig into their own pockets – often at great personal sacrifice – to obtain an appropriate education for their disabled child in the face of the public school system's failures.

This remedy is particularly important to the parents of children with autism spectrum disorders, a population of parents that has grown exponentially in recent years. Until relatively recently, autism was a rarely-diagnosed and little-known condition, but is now more prevalent among children than Down syndrome, diabetes, cystic fibrosis, and cancer. With about 1 in 150 children in the United States suffering from autism spectrum disorder, this is the fastest-growing segment of the IDEA-covered population. As thousands of children are newly diagnosed every year, more parents become familiar with the burdens – emotional and financial – that accompany a diagnosis of autism spectrum disorder.

Because effective programs can be expensive to implement and require personnel with specialized training, parents sometimes face resistance from their public school system. This is far from universally true – more and more public school systems are becoming ready, willing and able to provide appropriate and effective services for autism. But there is a nationwide shortage of the specially-trained personnel needed to implement effective interventions, and federal studies show that the availability of effective programs for children with autism varies substantially from state-to-state and district-to-district.

Parents unlucky enough to live in districts that cannot or do not provide appropriate services are faced with the painful choice of accepting an educational placement that will damage their child's development or taking the risk of securing appropriate services on their own and seeking reimbursement.

Since autism frequently is not identified until the child is already school-aged, a significant number of parents will face this difficult choice when their child has never received any special education or related services from the public school system. The Petitioners and the *amici* who support them ask this Court to turn an otherwise risky choice for these parents into a draconian one – either accept inappropriate services that threaten to permanently and immeasurably retard their child's capacity for progress; or reject the proposed placement and secure appropriate services cut of their own pockets, with no prospect of reimbursement for the tremendous financial sacrifices they will make. In some circumstances, Petitioner's proposed rule would deny parents reimbursement even though the school district failed to offer any special education services at all. Meanwhile, other families whose children have received services unrelated to the inappropriate placement – because their child was initially misdiagnosed, because the family moved to a new school district, or for a multitude of other reasons – would remain free to reject the inappropriate placement without sacrificing their eligibility for reimbursement. No coherent rationale, statutory or otherwise, supports subjecting parents already struggling with the unique hardships of raising a child with autism to the cruel dilemma urged by Petitioner, and no rational justification warrants treating similarly-situated families so differently.

## I. FOR AN EVER-GROWING POPULATION OF CHILDREN DIAGNOSED WITH AUTISM SPECTRUM DISORDERS, A FALSE START OR EDUCATIONAL MISSTEP CAN BE DEVASTATING

The devastating impact of autism is being experienced by an ever-growing number of families, as the incidence of autism spectrum disorder has risen dramatically in recent years. But as more and more families come to understand the financial and emotional burdens of grappling with this disorder, a scientific consensus has developed that early, intensive educational services offer children the prospect of ameliorating and even overcoming the developmental deficits associated with autism. With appropriate educational services, almost all children with autism can become more independent, and many can now claim realistic prospects for becoming self-sufficient. Some will even improve to the point where they appear indistinguishable from their non-disabled peers, participating in regular education classrooms alongside them. But these interventions are most effective when children with autism can be identified and served early; as children grow older, our ability to positively affect their development diminishes. An inappropriate educational placement, then, can have a devastating impact on a child's future. Even if the child later receives appropriate services, potential for improvement will have irreversibly slipped away with the passing of time.

### A. As the Incidence of Autism Spectrum Disorder Has Mushroomed, Congress Increasingly Has Treated Autism as a National Priority

In recent years, autism has grown dramatically more prevalent. In 1961, it was confidently asserted that "[i]nfantile autism is a relatively rare form of schizophrenia and is not important from an epidemiological point of view." C.B. Ferster, *Positive Reinforcement and Behavioral Deficits of Autistic Children*, 32 CHILD DEVELOPMENT 437, 437 (1961), *reprinted in* CLASSIC READINGS IN AUTISM 53 (Anne M. Donnellan ed., 1985). Even in 1993,[3] shortly after the Department of Education began collecting statistics on autism, it classified only 19,058 children between 6 and 21 as having autism. 2 OFFICE OF SPECIAL EDUC. AND REHABILITATIVE SERVS., DEP'T OF EDUC., 26TH ANNUAL (2004) REPORT TO CONGRESS ON THE IMPLEMENTATION OF THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT 25 (2006).[4] But in 2005, the Department of Education reported 192,643 autistic students between the ages of 6 and 21 – a more than tenfold increase. Office of Special Education and Rehabilitative Services, Office of Special Education Programs, U.S. Department of Education, Data Analysis System (DANS), 1976-2005, *Table 1-3, Students ages 6 through 21 served under IDEA, Part B, by disability*

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[3] Autism was added as a specifically-identified category of disability under IDEA by the Education of the Handicapped Act Amendments of 1990, Pub. L. 101-476, § 101, 104 Stat. 1103, 1142 (1990). It is very difficult to determine the prevalence of autism before the 1990s.

[4] Available at http://www.ed.gov/about/reports/annual/osep/2004/26th-vol-2.pdf (accessed June 17, 2007).

*category and state: Fall 2005*.[5] The Centers for Disease Control report rates as high as 1 in every 150 children. Catherine Rice, *Prevalence of Autism Spectrum Disorders – Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002*, 56 MORBIDITY & MORTALITY WKLY. REV. SS-1 12, at 12 (Feb. 9, 2007) ("CDC, *14 Sites Study*").[6] With some 24,000 children with autism born each year, S. REP. NO. 109-318 at 3 (2006), autism spectrum disorder is now more common among children than Down syndrome, diabetes, cancer, cystic fibrosis, hemophilia, and sickle cell disease.[7]

As the incidence of autism has grown, Congress increasingly has made autism research and education a national priority. Autism was specifically identified as a disability under IDEA in 1991. *See* 20 U.S.C. § 1401(3)(a)(i); Education of the Handicapped Act Amendments of 1990, Pub. L. 101-476, Title I, § 101, Title IX, § 901(b)(10) to (20), 104 Stat. 1103, 1142, 1143 (1990). The Children's Health Act of 2000 directed the National Institutes of Health to expand and intensify autism research and mandated the creation of an Interagency Autism Coordinating Committee to coordinate autism research and other efforts within the Department of Health and Human

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[5] Available at http://www.ideadata.org/tables29th/ar_1-3.xls (accessed July 16, 2007).

[6] Available at http://www.cdc.gov/mmwr/PDF/ss/ss5601.pdf (accessed July 16, 2007).

[7] Figures available from the National Institutes of Health's National Human Genome Research Institute, http://www.genome.gov/10001204 (Down syndrome, cystic fibrosis, hemophilia, sickle cell disease), http://ndep.nih.gov/diabetes/youth/youth.htm (diabetes), and http://seer.cancer.gov/csr/1975_2004/results_merged/sect_28_childhood_cancer.pdf (cancer) (all sites accessed July 16, 2007).

Services. Pub. L. 106-310, Title I, 114 Stat. 1101 (2000). In 2004, IDEA was amended to encourage the Department of Education to support the development of programs to train special education teachers in autism disorders, 20 U.S.C. § 1462(b)(2)(G), and programs providing technical assistance and in-service training to schools and personnel servicing children with autism spectrum disorders, 20 U.S.C. § 1463(c)(8)(D). *See* Individuals with Disabilities Education Improvement Act of 2004, Pub. L. 108-446, Title I, 118 Stat. 2647, 2677 & 2682 (2004). Most recently, Congress enacted the Combating Autism Act of 2006 to, among other things, dramatically increase funding for autism research, detection and intervention and to promote interagency coordination of autism-related activities through the NIH. *See* Pub. L. 109-416, 120 Stat. 2821 (2006); S. REP. NO. 109-318 at 18-20.

### B. With Appropriate Educational and Related Services, the Developmental Deficits Associated with Autism Can Be Ameliorated or Overcome

Autism is a spectrum disorder encompassing a range of developmental disorders related to impaired social function, impaired communication and repetitive, stereotyped behaviors. The degree and manifestation of impairments can vary dramatically from individual to individual, and the spectrum of disorders includes Asperger's Disorder and Pervasive Developmental Disorder, Not Otherwise Specified ("PDD-NOS"). *See* DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS, FOURTH EDITION, TEXT REVISION at 69-75 (4th ed. 2000) ("DSM-IV-TR"); S. REP. NO. 109-318, 2-3 (Aug. 3, 2006). Most children with autism

show an "inability to relate themselves in the ordinary way to people and situations from the beginning of life. . . ." Leo Kanner, *Autistic Disturbances of Affective Contact*, 2 NERVOUS CHILD 217 (1943), *reprinted in* CLASSIC READINGS IN AUTISM, at 41 (Anne M. Donnellan ed., 1985) (emphasis omitted). Impaired communication is another classic symptom of autism. Approximately 40 percent of children with autism do not talk, and others have difficulty learning to use language for communicative purposes. S. REP. NO. 109-318 at 2; DSM-IV-TR at 70. Many children with autism also demonstrate restricted and stereotypical patterns of behavior or interests, an insistence on predictability, and great difficulty coping with unexpected changes to their routine. S. REP. NO. 109-318 at 3; DSM-IV-TR at 71.

Symptoms generally manifest early, usually before the child's third birthday and in some cases almost from birth. S. REP. NO. 109-318 at 3, 9; AUTISM SPECTRUM DISORDER EXPERT WORKING GROUP, INTERAGENCY AUTISM COORDINATING COMM., NAT'L INST. OF MENTAL HEALTH, DEP'T OF HEALTH AND HUMAN SERVS., AUTISM SPECTRUM DISORDERS ROADMAP 8 (May 16, 2005) ("ROADMAP").[8] Yet children with autism frequently are not identified until after they have entered the public school system. S. REP. NO. 109-318 at 3, 9; ROADMAP at 8.[9] Though symptoms often are apparent at

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[8] Available at http://www.nimh.nih.gov/autismiacc/asdroadmap.pdf (accessed July 16, 2007). The Working Group was created by the Interagency Autism Coordinating Committee at the National Institute of Mental Health. *Id.* at 2.

[9] With a median age at diagnosis of 52-56 months, half of autistic children are not diagnosed until they are nearly 5 years old or later. Catherine Rice, *Prevalence of Autism Spectrum Disorders: Autism and Developmental Disabilities Monitoring Network, Six Sites, United*

(Continued on following page)

a young age, they can be overlooked or mistaken for emotional disturbance, mental retardation or deafness and special training is required to recognize and properly diagnose the signs of autism.[10]

While the cause or causes of autism are still unclear, there is broad agreement that, if properly diagnosed at a young age, the symptoms of autism often can be significantly ameliorated through education. As discussed below, with appropriate and *early* intervention – as soon as possible, while the child's developing brain has the greatest degree of "neurologic plasticity" – it is possible for most children to make significant progress in communication, adaptive behaviors, and socialization. *See, e.g.*, Tristram Smith and O. Ivar Lovaas, *Intensive and early behavioral intervention with autism: the UCLA young autism project*, 10 INFANTS & YOUNG CHILD. 67, 69-72 (1998). Appropriate education offers the possibility that children with autism can achieve self-sufficiency and become functioning,

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*States, 2000*, 56 MORBIDITY & MORTALITY WKLY. REV. SS-1 1, at 1 (Feb. 9, 2007). In some locations, the median age of diagnosis is 66 months, meaning that half of children diagnosed with autism are not identified until after they are more than 5½ years old. CDC, *14 Sites Study* at 20.

[10] *See, e.g., M.S. v. Fairfax County Sch. Bd.*, No. 1:05cv1476(JCC), 2007 WL 1378545, at *4 (E.D. Va. May 8, 2007) (school board classified child as non-categorical with mild mental retardation and speech and language impairment and did not acknowledge that the child was autistic until he completed middle school); Carol Tavris, *Commentary: And Babies Don't Come From Storks, Either; Science: The Alleged Link Between Vaccines And Autism Is Just The Latest Example Of Finding Causation Out Of Coincidence*, L.A. TIMES, May 7, 2000, at M5 ("Autism is not easy to diagnose accurately, and is often misdiagnosed by public school personnel.") (internal quotations omitted).

contributing members of society rather than permanent financial and emotional burdens on their families and on the public treasury.[11]

### C. Taking Timely Advantage of the "Window of Opportunity" Is Critical to a Child's Ability to Remediate or Overcome the Symptoms of Autism

There is "abundant scientific evidence" that early, intensive instruction "can result in dramatic improvements for children with autism: successful integration in regular schools for many, *completely normal functioning* for some." Gina Green, *Early Behavioral Intervention for Autism*, in BEHAVIORAL INTERVENTION FOR YOUNG CHILDREN WITH AUTISM: A MANUAL FOR PARENTS AND PROFESSIONALS 29, 29 (Catherine Maurice et al. eds., 1996) (emphasis in original). Over the course of the last two decades, "virtually every study" has found that early and intensive intervention is effective, and there is now "little doubt" that appropriate intervention "can produce large, comprehensive, lasting and meaningful improvements in many important domains for a large proportion of children with autism." *Id.* at 38.[12]

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[11] For descriptions of autistic children who have grown into productive – even remarkable – adults, *see, e.g.*, OLIVER SACKS, AN ANTHROPOLOGIST ON MARS 244-296 (1995); CLARA CLAIBORNE PARK, EXITING NIRVANA (2001); STEPHEN M. SHORE, BEYOND THE WALL (2001); KAMRAN NAZEER, SEND IN THE IDIOTS (2006).

[12] *See* Geraldine Dawson and Julie Osterling, *Early intervention in autism*, in THE EFFECTIVENESS OF EARLY INTERVENTION 307, 314 (1997) (reviewing eight model early intervention programs and finding that "all of the programs were quite effective in fostering positive school placements, significant developmental gains, or both for a substantial

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Indeed, education is the primary treatment for autism.[13]

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percentage of their students"); Tristram Smith et al., *Intensive behavioral treatment for preschoolers with severe mental retardation and pervasive developmental disorder*, 102 AM. J. MENT. RETARD. 238, 238 (1997) (preschool children who received intensive behavioral treatment "made major increases in intellectual, academic, adaptive, and socio-emotional functioning"); *id.* at 246-47 (preschool children who received intensive behavioral treatment scored in the average range on standardized intelligence tests and performed satisfactorily in regular classes several years after the treatment, compared to only 2.5% of autistic children who received minimal treatment); John J. McEachin et al., *Long-term outcome for children with autism who received early intensive behavioral treatment*, 97 AM. J. MENT. RETARD. 359, 367-68 (1993) (autistic children who received early and intensive behavioral intervention prior to age 4 preserved their gains in intellectual and educational functioning at 13, and had average IQ scores which were 30 points higher than that of control subjects); Sandra L. Harris et al., *Changes in cognitive and language functioning of preschool children with autism*, 21 J. AUTISM DEV. DISORD. 281, 287 (1991) (IQ scores of young children increased an average of nearly 19 points after one year of intensive education); Sally J. Rogers and Hal Lewis, *An effective day treatment model for young children with pervasive developmental disorders*, 28 J. AM. ACAD. CHILD & ADOLESC. PSYCHIATRY 207, 207 (1989) (six months of intensive intervention resulted in significant gains "in cognition, perpetual/fine motor, social/emotional, and language skills, which were maintained or increased over a 12- to 18-month treatment"); O. Ivar Lovaas, *Behavioral treatment and normal educational and intellectual functioning in young autistic children*, 55 J. CONSULT. & CLIN. PSYCHOL. 3, 7-9 (1987) (47% of autistic children who received intensive behavioral intervention achieved normal-range IQ scores and successful performance in public schools, compared with only 2% of autistic children who received less intensive intervention); *see generally* Committee on Children With Disabilities, American Academy of Pediatrics, *Technical Report: The Pediatrician's Role in the Diagnosis and Management of Autistic Spectrum Disorder in Children*, 107:5 PEDIATRICS 85 (May 2001), available at http://pediatrics.aappublications.org/cgi/content/full/107/5/e85 (accessed July 17, 2007).

[13] *See* NAT'L RESEARCH COUNCIL, EDUCATING CHILDREN WITH AUTISM 12 (2001) ("Education ... is currently the primary form of treatment in autism."); Green, *supra*, at 29 (besides early, intensive instruction, "[n]o other treatment for autism offers comparable

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But the effectiveness of intervention depends on early application. Leading federal agencies, professional organizations and educational institutions all have stressed the importance of early intervention for children with autism.[14] Congress likewise has emphasized that "children with autism spectrum disorder identified early and enrolled in early intervention programs show significant

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evidence of effectiveness") (citations omitted); Smith & Lovaas, *supra*, at 68 (educational approaches to the treatment of autism have been empirically validated, but biomedical interventions "appear to do little to alter the outcomes of individuals with autism."); Lovaas, *supra* note 12, at 3 ("Medically and psychodynamically oriented therapies have not proven effective in altering outcome.").

[14] *See* NAT'L INST. OF HEALTH, DEP'T OF HEALTH AND HUMAN SERVS., AUTISM SPECTRUM DISORDERS: PERVASIVE DEVELOPMENTAL DISORDERS 17 (2007) ("One point that most professionals agree on is that early intervention is important."), available at http://www.nimh.nih.gov/publicat/nimhautismspectrum.pdf (accessed July 16, 2007); NAT'L INST. OF MENTAL HEALTH, DEP'T OF HEALTH AND HUMAN SERVS., REPORT TO CONGRESS ON AUTISM 2 (2006) ("Early intervention is critical for affected children to gain maximum benefit from current therapies."), available at http://www.nimh.nih.gov/autismiacc/autismreportFY2005.pdf (accessed July 17, 2007); Joicey Hurth et al., *Areas of agreement about effective practices among programs serving young children with autism spectrum disorders*, 12 INFANTS & YOUNG CHILD. 17, 21-26 (1999) (discussing general consensus that "[c]hildren who begin appropriate services earlier have better out-comes" and that the "earliest possible start to intervention" is an integral or defining part of the program); NAT'L RESEARCH COUNCIL, *supra* note 13, at 6 ("The committee recommends that educational services begin as soon as a child is suspected of having an autistic spectrum disorder."); *see generally* American Academy of Pediatrics, *supra* note 12. *See also* Cathryn Garland and Michael O'Hanlon, *Studying Autism Isn't Enough*, N.Y. TIMES (Nov. 21, 2006) ("There is broad consensus, as reflected in previous studies by the National Academy of Sciences and American Academy of Pediatrics, that early and intensive intervention is critical."), available at http://www.nytimes.com/2006/11/21/opinion/21ohanlon.1.html (accessed July 17, 2007).

improvements in their language, cognitive, social, and motor skills, as well as in their future educational attainment and decreased needs for special education services." S. REP. NO. 109-318 at 10. Intervention "should begin as soon as possible, preferably in the preschool years, because young children have not yet fallen as far behind their typically developing peers and may have more neurologic plasticity than older children." Smith & Lovaas, *supra*, at 68-69. During this period "the young, developing brain is very modifiable," Green, *supra*, at 39; and "rigorous behavioral therapy modifies the neural circuitry before the condition becomes permanent." LYNN M. HAMILTON, FACING AUTISM 92 (2000) (citations omitted); *see also* McEachin et al., *supra* note 12, at 371 ("[A]lterations in neurological structure are quite possible as a result of changes in the environment in the first years of life" and "intensive early intervention could compensate for neurological anomalies in such children.").

Children with autism cannot make up for lost time. When the opportunity presented during this window passes, the squandered potential cannot be regained later. "[B]oth popular literature and professional literature offer promises of positive development outcomes, even 'cure' or remediation of autistic symptoms, given early and intensive intervention. Families' desire for best outcomes is heightened by the threat that untreated, or inadequately treated, the syndrome can have devastating developmental impacts." Hurth et al., *supra* note 14, at 18. As the child grows older, he or she will "have a far more difficult time learning the skills that he needs to function in life." *J.H. ex rel. J.D. v. Henrico County Sch. Bd.*, 326 F.3d 560,

565 (4th Cir. 2003).[15] Losing this "valuable and unretrievable time" could mean that the child will "never develop to their full educational achievement level." *Noyes v. Grossmont Union High Sch. Dist.*, 331 F. Supp. 2d 1233, 1243 (S.D. Cal. 2004) (internal citations and quotations omitted), *rev'd sub nom., Evans v. Grossmont Union High Sch. Dist.*, Nos. 04-56341 & 04-56360, 197 Fed. Appx. 648 (9th Cir. Aug. 15, 2006) (reversing attorneys' fees award).

Similarly, gains made through appropriate interventions can be lost or reversed if the child is moved to an inappropriate placement. *See* Green, *supra*, at 30-31 ("One of the keys to producing lasting treatment gains in children with autism is consistency."); American Academy of Pediatrics, *supra* note 12. "Children with autism have a profound ability to regress," and if intensive treatment is not maintained consistently, "you have to go back and reinvent the wheel, not completely, not from the ground up, but you are going to have to go back and basically retool." *J.H. ex rel. J.D. v. Henrico County Sch. Bd.*, 395 F.3d 185, 190 (4th Cir. 2005) (quoting expert testimony). *See also Diatta v. Dist. of Columbia*, 319 F. Supp. 2d 57, 66 (D.D.C. 2004) (because of inappropriate placements, for

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[15] *See also Jaynes v. Newport News Sch. Bd.*, No. 4:99cv146, 2000 U.S. Dist. LEXIS 21684, at *1-2 (E.D. Va. Sept. 7, 2000), *aff'd*, 13 Fed. Appx. 166 (4th Cir. July 10, 2001) (neurologist testimony that "there's a window of opportunity and that window of opportunity is greatest between the age of discovery and as early as possible;" parents should "immediately, immediately do something fast, now, right now"); Anahad O'Connor, *In Autism, New Goal Is Finding It Soon Enough to Fight It*, N.Y. TIMES, Dec. 14, 2004 ("After a certain point, you can still teach an autistic child certain things, ameliorate destructive behaviors, but you're not really going to change the developmental pathway that they're on.") (quotation omitted), available at http://www.nytimes.com/2004/12/14/health/14/auti.html (accessed July 17, 2007).

the "foreseeable future" the child's education would be "remedial, in that educators, aides and his family will have to correct four years of mis-education").

Parents, then, simply cannot allow their child to languish in an inappropriate setting when every passing moment erodes potential benefits that can never be regained. For these children and their parents, "every moment counts." Laurie Tarkan, *Autism Therapy Is Called Effective, but Rare*, N.Y. TIMES, Oct. 22, 2002[16] (describing the "horrible feeling of time slipping away and nothing being done" when parents of children with autism do not have access to appropriate treatment); *see also County Sch. Bd. of Henrico County v. R.T.*, 433 F. Supp. 2d 692, 696 (E.D. Va. 2006) ("a critical window of developmental opportunity was closing" for a child who was not receiving an adequate public education). "Children with autism can't afford to waste a second. . . . With the right kind of early intervention, they can learn. Without it, there's no hope." Leslie C. Feller, *When Autistic Child's Growth Is at Stake*, N.Y. TIMES, Apr. 25, 1999 (internal quotation omitted).[17] Forcing a child with autism into a patently inappropriate placement can have a calamitous and irreparable impact on the long-term development of the child, a circumstance no parent should have to face.

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[16] Available at http://query.nytimes.com/gst/fullpage.html?sec=health&res=9C05E0D71F3DF931A15753C1A9649C8B63 (accessed July 17, 2007).

[17] Available at http://query.nytimes.com/gst/fullpage.html?sec=health&res=9503E2D9143AF936A15757C0A96F958260 (accessed July 17, 2007).

## II. MANY PUBLIC SCHOOLS ARE UNABLE TO PROVIDE APPROPRIATE EDUCATIONAL SERVICES TO ALL OF THEIR AUTISTIC STUDENTS

An appropriate placement requires the application of research-based methodologies by specially-trained personnel. This requires both an appropriately-designed program and personnel to implement it – both of which are in short supply all across the nation. The Autism Spectrum Disorder Expert Working Group has found that effective services "tend to be scattered, fragmented, and poorly coordinated. . . . Even where services are available, public and private financing are often inadequate to meet the needs of most individuals with ASD [autism spectrum disorder] and their families." ROADMAP at 3. The Working Group found "a serious and persistent lack of adequate capacity to provide appropriate care for children, adolescents, youth, and adults with ASD." *Id.* at 10. A recent CDC study found that as many as 38% of 8-year-old children with autism spectrum disorders were not receiving special education services in some locations, and that in many locations the majority of children did not receive special education services under the primary category of autism. CDC, *14 Sites Study* at 19.

Even when appropriate programs are available, there often is a lack of qualified personnel to implement the program for all children with autism. Special education teachers are in chronically short supply. Erling E. Boe, *Long-Term Trends in the National Demand, Supply and Shortage of Special Education Teachers*, 40:3 J. SPECIAL EDUC. 138, 138-150 (Sept. 2006); James McLesky et al., *The Supply of, and Demand for, Special Education Teachers*, 38:1 J. SPECIAL EDUC. 5, 5-21 (Mar. 2004). As the National Research Council has observed, "that shortage is

even more serious in the growing field of autistic spectrum disorders." NAT'L RESEARCH COUNCIL, *supra* note 13, at 184; *see also id.* at 186 ("Personnel preparation has become an increasingly well-publicized issue as the number of children identified with autistic spectrum disorders has increased and their special needs have become more evident."). With thousands of children newly diagnosed with autism each year, this shortage is likely to become even more severe. Thus, "[i]t is possible that even a well designed special education program for a school district could still fall short of adequately providing for the special needs of children with autistic spectrum disorders." NAT'L RESEARCH COUNCIL, *supra* note 13, at 182. The National Research Council concluded that "[o]ne of the clear needs in the field of autism is to increase the number of well-prepared professionals to work with children and their families." *Id.* at 190. This is not to say that public schools are incapable of meeting the needs of children with autism; many school systems do have appropriate, adequately-staffed programs. But many do not, and the parents of children living in these districts must look elsewhere to find appropriate services for their children. *See, e.g., A.K. ex rel. J.K. v. Alexandria City Sch. Bd.*, 484 F.3d 672, 681-82 (4th Cir. 2007) (no public school existed that could adequately meet the needs of a child with autism).[18]

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[18] School systems may also deny children with autism a free appropriate public education by failing to recognize a child's disability, *see, e.g., Bd. of Educ. of Montgomery County v. S.G.*, No. 06-1411, 2007 WL 1213213 at *3-4 (4th Cir. Apr. 25, 2007) (*per curiam*) (unpublished); *Scott v. Dist. of Columbia*, No. 03-1672 DAR, 2006 WL 1102839, at *7-9 (D.D.C. Mar. 31, 2006); by failing to formulate an individualized education plan ("IEP") in a timely manner, *Gadsby ex rel. Gadsby v.*

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Forcing parents to shoulder the full financial impact of a school district's inability or unwillingness to provide appropriate services would be crushing for most families. The financial burdens of raising a child with autism can be immense. Private service providers can cost up to $50,000 a year or more. THE BROOKINGS INST. AND THE HELP GROUP, CONFERENCE REPORT: AUTISM AND HOPE at 5 (2006).[19] The median income for an American household in 2005, in comparison, was $46,326. U.S. CENSUS BUREAU, U.S. DEP'T OF COMMERCE, INCOME, POVERTY, AND HEALTH INSURANCE COVERAGE IN THE UNITED STATES: 2005, at 5 (2006).[20] Services for children with autism are rarely covered by private health insurance, even assuming the parents are insured. ROADMAP at 16; Milt Freudenheim, *Battling Insurers Over Autism Treatment*, N.Y. TIMES, Dec.

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*Grasmick*, 109 F.3d 940, 945 (4th Cir. 1997); *Gabel ex rel. L.G. v. Bd. of Educ. of Hyde Park Cent. Sch. Dist.*, 368 F. Supp. 2d 313, 321 (S.D.N.Y. 2005); *Solomon-Lane v. Dist. of Columbia*, No. 99-2404(RWR), 2005 WL 736533, at *1 (D.D.C. Mar. 31, 2005); *Justin G. ex rel. Gene R. v. Bd. of Educ. of Montgomery County*, 148 F. Supp. 2d 576, 583 (D. Md. 2001); by developing an IEP in such flagrant violation of IDEA's procedural requirements that it amounts to the denial of a free appropriate public education, *see, e.g.*, *Deal v. Hamilton County Bd. of Educ.*, 392 F.3d 840, 855-61 (6th Cir. 2004); *W.G. v. Bd. of Trs.*, 960 F.2d 1479, 1481-82, 1484-85 (9th Cir. 1992); *Spielberg v. Henrico County Pub. Sch.*, 853 F.2d 256, 259 (4th Cir. 1988); or by refusing to integrate children with autism into regular education classrooms, where they can address the core deficits of autism: social skills, communication and spontaneity, *see, e.g.*, *L.B. ex rel. K.B. v. Nebo Sch. Dist.*, 379 F.3d 966, 971-72, 978 (10th Cir. 2004); 20 U.S.C. § 1412(a)(5)(A).

[19] Available at http://www.brookings.edu/dybdocroot/comm/conferencereport/20051216autism.pdf (accessed July 17, 2007).

[20] Available at http://www.census.gov/prod/2006pubs/p60-231.pdf (accessed July 16, 2007).

21, 2004.[21] If both parents work, one parent often goes part-time or quits entirely to devote more time to raising the child – magnifying the financial impact of raising a child with autism. *See, e.g.*, Stephanie Rosenblum, *The Neediest Cases: Putting Their Son, Who Is Autistic, First*, N.Y. TIMES, Jan. 15, 2005;[22] John O'Neil, *One Boy's Journey Out Of Autism's Grasp*, N.Y. TIMES, Dec. 29, 2004.[23] A child with autism is a gift and a joy, but there is no denying that the additional monetary and emotional costs of raising such a child can weigh heavily on the family. NAT'L RESEARCH COUNCIL, *supra* note 13, at 33-35; *see also* Victoria Clayton, *How Families Connect to Cope with Autism*, MSNBC.com, Feb. 24, 2005 ("Besides the anxiety and the high demands on parents' time and energy, autism can also take a heavy toll on family finances and put a big strain on relationships.").[24]

## III. CONGRESS DID NOT INTEND TO FORCE PARENTS TO CHOOSE BETWEEN SACRIFICING THEIR CHILD'S DEVELOPMENT OR SACRIFICING THEIR RIGHT TO A FREE PUBLIC EDUCATION

As the Court observed two decades ago, IDEA does not require parents to choose between an appropriate education

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[21] Available at http://www.nytimes.com/2004/12/21/business/21autism.html (accessed July 16, 2007).

[22] Available at http://query.nytimes.com/gst/fullpage.html?res=990DEFDF1538F936A25752C0A9639C8B63 (accessed July 17, 2007).

[23] Available at http://www.nytimes.com/2004/12/29/education/29autism.html (accessed July 17, 2007).

[24] Available at http://www.msnbc.com/id/6988852 (accessed July 16, 2007).

and a free one. *Sch. Comm. of Burlington v. Dep't of Educ.*, 471 U.S. 359, 370 (1985). Especially in light of Congress's repeated recognition that early and appropriate intervention is critical for children with autism, *see supra* pp. 7-8, 13-14; and the broad consensus on the damaging and irreversible consequences of committing a child to an inappropriate placement, *supra* pp. 13-16; IDEA should not be interpreted to force parents faced with an inappropriate placement from the school district to choose between sacrificing their child's development or sacrificing their right to seek reimbursement for proper services.

### A. Petitioner's "Give It a Try" Theory Is Inconsistent with IDEA's Statutory Structure and Legislative History

Petitioner and its *amici* contend that a prior-receipt-of-services requirement advances a Congressional decision to encourage parents to give an inappropriate public placement a "try" before rejecting it. Br. for Pet'r at 22, 37; Br. *Amici Curiae* NSBA and AASA at 11. But the legislative history and statutory structure disclose no evidence that Congress intended to adopt a "give it a try" requirement that would force parents to either accept inappropriate placements, or instead sacrifice their rights to reimbursement. To the contrary, Congress has repeatedly demonstrated its appreciation of the critical importance of taking advantage of the developmental window for children with autism through early identification and appropriate intervention. *See* 20 U.S.C. §§ 1401(3)(a)(i), 1462(b)(2)(G), 1463(c)(8)(D); Pub. L. 106-310, Title I, 114 Stat. 1101; Pub. L. 109-416, 120 Stat. 2821 (2006); S. REP. NO. 109-318 at 5, 9-10. Nothing in IDEA requires parents to "try out" an inappropriate IEP before initiating

administrative review proceedings, 20 U.S.C. § 1415(f); or requires a reviewing administrative hearing officer or court to wait until the child has given an inappropriate IEP a try before ruling on the merits and awarding appropriate relief. 20 U.S.C. § 1415(i)(2), (3). Indeed, a hearing officer or court is free to award injunctive relief requiring the school district to offer the child a private placement before the child has tried out the school district's placement. Yet Petitioner and its *amici* offer no rationale for distinguishing between monetary relief and injunctive relief that would have the same effect if the statute truly reflected a "give it a try" requirement.

### B. Petitioner's "Give It a Try" Theory Would Lead to Unjust and Irrational Results

In light of the limited availability of appropriately-designed programs for children with autism, the chronic shortage of properly-trained personnel to staff them, *see supra* pp. 17-18; and the ever-growing numbers of newly-diagnosed children, *supra* pp. 6-7; a significant number of families are likely to encounter an inappropriate IEP before their child has received any special education or related services from the school district. On the one hand, these parents could accept the inappropriate services for the time being in order to become eligible for reimbursement if they later secure appropriate services at their own expense – but an inappropriate placement can cause irreparable damage to a child's chances for improvement and prevents the child from taking advantage of the window when the opportunities for progress are the most promising. On the other hand, parents can do what they believe is best for their child by securing appropriate

services at their own personal expense and pursuing their rights in the administrative and judicial review process.

If Petitioner's view of IDEA were accepted, these parents could never be reimbursed for these expenses, even if they prevail on the merits in administrative proceedings and litigation. Instead, they would be forced to shoulder the severe financial impact on their own. *See supra* pp. 19-20. And in many cases, parents would have to continue paying for private services until the school district began providing appropriate services pursuant to an administrative or court order. As the Court has noted, this process can be extraordinarily lengthy. *See Burlington*, 471 U.S. at 370. Parents would be in exactly the position the Court rejected in *Burlington*: winners of an "empty victory" when "a court tell[s] them several years later that they were right but that these expenditures could not in a proper case be reimbursed. . . . [T]he child's right to a *free* appropriate public education, the parents' right to participate fully in developing a proper IEP, and all of the procedural safeguards would be less than complete." *Id.* (emphasis in original).

### 1. Petitioner's "Give It a Try" Theory Would Irrationally Treat Similarly-Situated Parents Differently

Moreover, the prior-receipt-of-services condition for reimbursement proposed by Petitioner would serve its hypothesized "give it a try" policy so poorly that it is simply implausible that Congress had any such policy in mind. An IEP can be inappropriate for any number of reasons having nothing to do with the services a child has received in the past, yet the mere fact that the child received unrelated past services would exempt the parents

from Petitioner's "give it a try" requirement. Petitioner thus would treat similarly-situated parents differently with no rational basis for doing so.

***Parents of misdiagnosed children***. For example, a child could receive special education and related services for the wrong disability because he or she was misdiagnosed – a serious problem for children with autism, who sometimes are mistaken for being deaf, mentally retarded or emotionally disturbed. *See supra* p. 10. The school district may offer fine services for deaf children, but completely inadequate services for children with autism. Yet, the parents of a child who mistakenly received special education or related services for deafness could reject the inappropriate autism placement and be reimbursed for their personal expenditures on appropriate services, while the parents of a newly-diagnosed child would not.

***Parents who move***. Or parents may move from one school district where their child received appropriate services for autism to another school district with a different, inappropriate program. The parents who moved could reject the inappropriate placement and retain their eligibility for reimbursement because their child had previously received services under the authority of a public agency – albeit a different public agency – while parents of children who grew up in the district would be subjected to the "give it a try" requirement.

***Parents whose children are diagnosed early***. Similarly, a school district could have an appropriate program for very young children, but an inadequate program for older children. Parents of children who were diagnosed young enough to take advantage of the early education program would be exempt from the "give it a

try" requirement if they chose to reject the program for older children, yet parents of later-diagnosed children with autism would not. Indeed, not only would parents of the earlier-diagnosed child be exempt from "trying out" the new, inappropriate placement in order to remain eligible for reimbursement if they chose a private placement instead, but they actually could prohibit the school district from seeking to try out the new placement by initiating administrative proceedings and invoking IDEA's "stay put" provision, 20 U.S.C. § 1415(j).

In contrast to Petitioner's treatment of parents who would be eligible for reimbursement, despite the fact that they had never given the particular placement at issue a try, Petitioner would bar parents whose children had never received special education and related services from any school district from reimbursement if they rejected the inappropriate placement, notwithstanding the fact that the parents gave the school the required notice of their intent to enroll their child in private school under 20 U.S.C. § 1412(a)(10)(C)(iii)(I), that the services offered by the school district were inappropriate, that the private school placement was proper, that the expenditures were reasonable, and that the equities weigh in favor of reimbursement. *See Florence County Sch. Dist. v. Carter*, 510 U.S. 7, 12-13, 16 (1997); *Burlington*, 471 U.S. at 370, 374; 20 U.S.C. § 1412(a)(10)(C)(iii)(III).

### 2. Petitioner's "Give It a Try" Theory Would Bar Reimbursement Even When There Is No Placement to Try

Indeed, Petitioner would deny parents reimbursement even when there is no public placement to "try" – as when the school district does not develop a timely IEP, *see, e.g.*,

*Gadsby ex rel. Gadsby v. Grasmick*, 109 F.3d 940, 945 & 950 (4th Cir. 1997); *Gabel ex rel. L.G. v. Bd. of Educ. of Hyde Park Cent. Sch. Dist.*, 368 F. Supp. 2d 313, 321-22, 324 (S.D.N.Y. 2005); *Justin G. ex rel. Gene R. v. Bd. Educ. of Montgomery County*, 148 F. Supp. 2d 576, 583-84 (D. Md. 2001); or when the school district fails to recognize the child's disability, *see, e.g., Bd. of Educ. of Montgomery County S.G.*, No. 06-1411, 2007 WL 1213213 at *3-4 (4th Cir. Apr. 25, 2007) (*per curiam*) (unpublished); *Scott v. Dist. of Columbia*, No. 03-1672 DAR, 2006 WL 1102839, at *7-9 (D.D.C. Mar. 31, 2006). In these circumstances, the school district has not offered any special education or related services, yet Petitioner's proposed rule *still* would force parents to bear the full cost of proper services on the Kafkaesque rationale that the school district had never provided any services. Similarly, Petitioner would deny parents reimbursement even where the school district *conceded* that its proposed placement was inappropriate, *see, e.g., Frank G. v. Bd. Educ. Hyde Park*, 459 F.3d 356, 361 (2d Cir. 2006), or if the IEP process was so plagued by procedural deficiencies that no reasonable parent could have faith in the appropriateness of the recommended placement, *see, e.g., Deal v. Hamilton County Bd. of Educ.*, 392 F.3d 840, 855-61 (6th Cir. 2004); *W.G. v. Bd. of Trs.*, 960 F.2d 1479, 1481-1482, 1484-85 (9th Cir. 1992); *Spielberg v. Henrico County Pub. Sch.*, 853 F.2d 256, 259 (4th Cir. 1988).

### 3. The Statute Does Not Contemplate How Long Parents Would Be Obligated to Try Out an Inappropriate Placement

The irrationality of Petitioner's proposal is further highlighted by the fact that the statute contains absolutely

no provision for how long a child would be required to give an inappropriate placement a try. Must the child try out the school district's inappropriate placement for the entire school year? For a semester? For a day? If one day is enough to satisfy Petitioner's proposed requirement, then the "give it a try" requirement would be absolutely useless for Petitioner's proposed purpose of giving the public placement enough time to show evidence of its success or failure. On the other hand, the longer the time requirement, the more severe and irreversible impact of the inappropriate placement on the parents and the child, as discussed *supra* pp. 13-16.

Even if Petitioner were correct that the statutory language unambiguously supports its interpretation, the consequences of that interpretation are so unjust and irrational that Congress cannot be presumed to have intended them. *Nixon v. Missouri Mun. League*, 541 U.S. 125, 138 (2004); *United States v. X-Citement Video, Inc.*, 513 U.S. 64, 69 (1994); *Pub. Citizen v. United States Dep't of Justice*, 491 U.S. 440, 454 (1989); *Green v. Bock Laundry Mach. Co.*, 490 U.S. 504, 509 (1989). But as the Brief for Respondent discusses, the statutory language and structure do not mandate or support the construction Petitioner urges. And as explained above, Petitioner's interpretation of the statute is contrary to the statutory structure and legislative history. Indeed, the distinctions that Petitioner's interpretation of IDEA would draw between similarly-situated families so defy rational justification that they would raise serious questions of equal protection, *Village of Willowbrook v. Olech*, 528 U.S. 562, 565 (2000), and the statute should not be construed to implicate these constitutional concerns. *See Gonzales v. Carhart*, ___ U.S. ___, 127 S. Ct. 1610, 1631 (2007) (citing

*Edward J. DeBartolo Corp. v. Florida Gulf Coast Bldg. & Constr. Trades Council*, 485 U.S. 568, 575 (1988)). Instead, IDEA should be interpreted consistent with its statutory structure and legislative history, and in a manner that avoids the unjust and irrational results that would flow from Petitioner's construction: parents who reject an inappropriate placement from the public school district should be able to seek reimbursement for reasonable expenses incurred securing proper, private services, thus ensuring their rights and their child's rights to an education that is both free and appropriate. *Burlington*, 471 U.S. at 370.

## CONCLUSION

For the foregoing reasons, *amicus curiae* Autism Speaks respectfully requests that the Court affirm the judgment of the Court of Appeals for the Second Circuit, and grant such other and further relief as it deems just and proper.

Respectfully submitted,

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